

New Challenges for a New Century

In 1975, when the Arkansas Spinal Cord Commission (ASCC) was established, if you sustained a spinal cord injury (SCI), you spent months and months in the hospital, ended up in a 65 pound wheelchair, were told that sex and having children were no longer part of your life and, basically, were left on your own to find what you needed. How things have changed!

“New Challenges for a New Century,” ASCC’s biannual conference, **June 2, 2000**, is an opportunity to learn about changes in technology, treatment, wellness and services. It is a chance to see old friends, meet new ones and see the latest equipment on the market.

David Kiley, Director of the Adaptive Sports and Adventure Program

at Charlotte Rehabilitation in North Carolina, will kick off the conference with his challenge, “What’s Your Excuse?” Kiley, a premier wheelchair athlete, disability advocate and motivational speaker who recently returned from a speaking tour in Africa, uses his own 25 years of experience with spinal cord injury to issue his challenge to groups all over the world.

Psychologist **Dr. Tim Elliott** from the Spain Rehabilitation Center in Birmingham, AL will share his insights and research on stress management, depression and dealing with spinal cord injury for people with SCI, as well as family members and caregivers. **Dr. Steve Sloan** from the Shepherd Center in Atlanta, GA will

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David Kiley, wheelchair athlete and disability advocate, will be the keynote speaker at the June 2, 2000, conference.

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New Case Manager in the Little Rock Office

Bernie Quell joined the Little Rock Case Management staff in March, replacing Brad Barber who left to work for a Norwegian cruise line. Bernie assumed the Case Management responsibilities for South Pulaski and part of Saline County.

For the past four years, Bernie has been the Director of Education and Compliance with Hospice Home Care, Inc. His primary job responsibilities during that time included staff development, inservice and volunteer training, conducting bereavement support groups and providing individual counseling. Bernie, also, has over ten years experience with job development and the vocational rehabilitation field.

Besides coming to the Commission with an excellent professional background, Bernie has a Masters degree in Rehabilitation Counseling from the University of Arkansas. He is also a Certified Rehabilitation Counselor and a Licensed Professional Counselor.

Last year Bernie had the misfortune of experiencing, as he so aptly puts it, “a major life altering event.” His home was severely damaged during the tornado that devastated the downtown Little Rock area. It has been a slow process putting the pieces back together. He and his wife have tried to maintain some semblance of normalcy during this time.

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SPINAL COURIER

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ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800-459-1517/TDD 501-296-1974**, or send your donation to:

AR Spinal Cord Commission
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In Memory of Steve Little
Gene Little

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Hello, Outdoor Enthusiast!

Dear Editor:

Readers of the *Spinal Courier* are invited to a fish fry sponsored and hosted by the Arkansas Disabled Sports Association (ADSA) on **July 29, 2000**, at Greers Ferry, AR.

The ADSA has a complete new Board of Directors and would like to meet with people who have an interest in outdoor activities. We

would love the opportunity to listen to you and your family about activities you enjoy doing. This will also give you an opportunity to find out what ADSA is all about. Remember to RSVP to **Toney LeQuieu** at **870-933-5254** or **Jimmy Ashley** at **870-935-6875**.

I hope to see you on the 29th of July!

Toney LeQuieu
Jonesboro, AR

From the Director

I've never been much for horror stories, murder mysteries or science fiction in books or movies. I've never read Stephen King—I don't like to be scared! So I'm not sure why it is that I read the newspaper everyday. Some days, the reports I read are worse than any fiction writer could come up with, but I keep reading, every morning like clock work.

I love sports, so I was heartbroken to read that Kansas City Chief football player Derrick Thomas had joined the ranks of the SCI and then, only a few weeks later, died from a pulmonary embolus (blood clot to the lungs). What a spokesperson he could have been for our causes! He was already a well known volunteer in his football home in Kansas City and his hometown of Miami. Maybe he can still be an example. Three people were in the Thomas' car, headed to the airport, traveling too fast on icy roads. One passenger died at the scene, Derrick sustained a spinal cord injury that cost him his life and the third passenger walked away with minor injuries. The difference? Guy #3 wore his seatbelt; the other two were thrown from the car. The life of an exceptional athlete, role model and philanthropist ended at 32, because he didn't buckle up. Now **that is** a horror story! Two needless deaths when one second to click might have saved them. Accidents don't just happen to star athletes. Seat belts can save YOU too; **please buckle up!**

Once in a while, the news is good! Just this morning I read that Michael Marion, Manager of the new Alltel arena, announced that arena security would be cracking down on those who misuse handicapped parking spaces at the Arena. It seems the staff has noticed apparently able-bodied folks leaving cars with handicapped plates. According to Marion, the staff will be checking the plates to see who they are registered to and checking identification of vehicle passengers. He noted the new increased fine should deter abusers once they know they are being checked! I hope he's right. I hope his guys are out there checking at every event, not just the ones that are sold out. Maybe it will catch on! Maybe its stories like this that keep me reading every morning.

See you at our conference, June 2. It's going to be great, don't miss it!

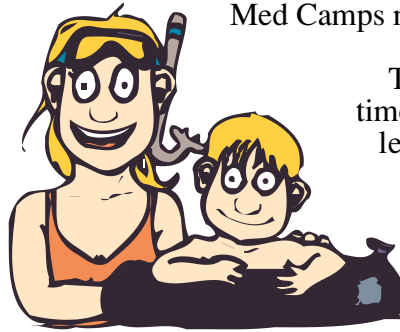
Cheryl Vines

♪ We Don't Know What You've Been Told, But Aldersgate's The Place To Go ♪

Spring has arrived and it is time to get ready for our annual Spina Bifida Camp. Every year the Arkansas Spinal Cord Commission, in cooperation with Med Camps of Arkansas, Inc. and Camp Aldersgate, Inc., sponsors a week long session of camping for children between the ages of six and sixteen at Camp Aldersgate in West Little Rock. This year's camp will be held from **June 25 through June 30, 2000.**

For those of you unfamiliar with camp, Camp Aldersgate is located in West Little Rock near Baptist Medical Center. Traditional camping ac-

tivities such as nature hikes, outdoor cooking, swimming, fishing, drama, music and arts and crafts that have been adapted so that each camper can participate to his or her fullest ability are featured. All of the cabins, dining hall, health care center and activity buildings are air conditioned and fully accessible. In addition, from the time camp starts on Sunday afternoon until camp ends on Friday morning, the campers are supervised by trained counselors, volunteers and



Med Camps medical specialist.

This really is a time of growth and learning for all of the campers while they spend a week full of fun-filled activities. Applications and brochures will be sent out in March

and acceptance will be on a first-come, first-served basis—so be sure to send yours in as soon as possible!

Medicaid Coverage Expands to Cover Orthotics and Prosthetics for Adults

Effective March 1, 2000, the Arkansas Medicaid program expanded the scope of their service coverage to include orthotic and prosthetic devices, according to DHS Medicaid Director **Ray Hanley**. These were previously available to children with Medicaid coverage and now will cover Medicaid recipients over the age of 21. "Once again, we are proud that Arkansas Medicaid has expanded their scope of services to meet this very important need," said ASCC Executive Director **Cheryl Vines** upon learning the news.

This coverage will include medically prescribed (with physicians prescription) equipment such as hand orthoses and splints, long and short leg braces and AFOs, artificial limbs for amputees, orthopedic shoes and devices and thoracic braces and corsets for trunk stability. Prior authorization is required for orthotic devices over \$500 and prosthetic devices over \$1,000. A \$3,000 maximum benefit per state fiscal year for orthotic devices and \$20,000 maximum benefit per state fiscal year for

prosthetic devices have been established for the new program.

Complementing the addition of durable medical equipment to the Medicaid scope of services in 1997, this new service will allow many Medicaid recipients to obtain needed equipment to improve their mobility and dexterity. To learn more about the covered services, contact your physician or local orthotics and prosthetics provider.

"As always, we caution our clients and other Arkansans to work with reputable, certified orthotists and prosthetists to obtain their equipment," said Vines. "This will assure you get what you need and what your physician prescribed." And she cautioned, "Be wary of ordering from catalogues, websites or television ads who offer 'custom' services but never see you in person. All orthotics and prosthetics should be fitted to the user by a professional." ASCC Case Managers can help clients locate certified providers for these important services.

Medicare Clarification Regarding Catheterization

In October 1999, the Department of Health and Human Services (DHHS) Health Care Financing Administration (HCFA) issued a program memorandum clarifying that sterile intermittent catheterization is covered under Medicare Part B under certain conditions.

In lay terms, the memorandum states that people with spinal cord injury and others with neurogenic bladder who (1) are Medicare eligible, (2) use a clean intermittent catheter technique and (3) have recurring UTIs can receive sterile catheters at Medicare expense.

If you encounter difficulties in obtaining Medicare payment for sterile catheters, cite this HCFA Program Memorandum and its Transmittal Identification Number, **AB-99-74**. HCFA's web site has additional information at **www.hcfa.com**.

Caveat Emptor: "Buyer Beware"

by Tom Kiser, M.D., ASCC Medical Director

Caveat emptor, a Latin phrase used in legal jargon, simply states that the buyer takes the risk of quality on him or herself. This is what you do when you get a new wheelchair from a dealer advertised on television or from a wheelchair supplier who comes to you. You are taking the responsibility on yourself that the wheelchair you are getting is the right one for you, and the dealer you are working with is going to stand behind the wheelchair he sells you.

A wheelchair is an essential piece of equipment in the life of someone living with paraplegia or tetraplegia. The wheelchair must fit well, provide good pressure distribution to your skin and be able to handle the demands you put on it. For someone with tetraplegia and unable to conduct the necessary pressure relief it may need a tilt and/or recline system to provide a method of pressure

If it sounds too good to be true it usually is, and you will pay dearly in the end.

relief. The other aspect you must consider is that no matter how careful you are in picking the proper wheelchair there is usually some aspect to the chair that needs to be changed. You want a vendor who is going to work with you to make the needed changes to the wheelchair.

I have the opportunity to be involved in a clinic helping people with spinal cord injury get the proper wheelchair for them. However, lately I have noticed quite a few individuals who have been provided a wheelchair from a local supplier which does none of the above, or the wheelchair is falling apart and the person who sold them the wheelchair either cannot or will not do the necessary repairs. This is a very disturbing to

me because often there is nothing I can do to help.

If their insurance paid for that wheelchair, it usually will not pay for another wheelchair for at least five years and sometimes even longer. The chances to make the situation better are usually not very good. Oftentimes the Spinal Cord Commission gets involved, but when you are discussing an expensive wheelchair there is only so much that can be done. I do not want to see any of you in that situation, so I recommend you take the following steps when you are thinking of getting a new wheelchair.

1. If someone **comes to you** wanting to sell you a wheelchair, **be leery**. (If a car salesman came to my door pushing Yugos (or a Lexus) the alarm bells would go off in my head.)
2. If you feel you may need a new wheelchair, **be an informed consumer** and get information about all the different wheelchairs. Talk to someone in a similar situation and ask him or her about their wheelchair.
3. **Call your Case Manager**. He or she is aware of different medical suppliers and their reputations. The Case Manager can usually tell you if they have a good or poor history of service.
4. Ask your doctor to send you to a **wheelchair clinic**. Oftentimes they can show you different wheelchairs and give you the opportunity to see the different models and styles.

You can avoid these problems by not getting a wheelchair from anyone who comes to your door or advertises on television. They promise to fit and service the wheelchair from the comfort of your own home. I know this is tempting, and almost



sounds too good to be true. In a perfect world this is how it should be, but we do not live in a perfect world, as you are all aware. If it sounds too good to be true it usually is, and you will pay dearly in the end.

Take the extra effort to check out the person selling you a wheelchair. Ask for references of 3 or 4 other customers and then call them and see how they feel about their wheelchairs and the service. Talk with your Case Manager, call the Spinal Cord Commission, but most of all, **buyer beware**. If you get a lemon from someone selling wheelchairs who is not reputable you are stuck, but someone who stands behind their work will make it right.

Attention Kids of All Ages!

The Archview Puppeteers will present a kids show on **Saturday, April 15, 2000, at 2:00 p.m.** at the Easter Seals Children's Rehab Center Building, 3920 Woodland Heights Road, Little Rock, AR. The puppet show should last 20-25 minutes and is **free of charge**. Go to the Children's Rehab Center dining room through the "After Hours Entrance."

For more information call **Lonnie Green** or **Joe Wagner** at **501-888-1240**.

The More You Know About Pressure Sores . . .



A pressure sore develops because of decreased blood flow to an area of the body under pressure. Imagine using a water hose: if someone came along and stepped on the hose, the water would trickle or stop completely. The water would begin flowing again when the person stepped off the hose. Like the water in the hose, blood that brings oxygen and nutrients to skin cells can be cut off when **too much** (excessive) pressure is applied to skin for **too long** (prolonged). Without oxygen and nutrients the cells and tissue in an area can die. When the tissue dies, a sore is left. Skin can also be damaged due to falls, bumps, burns or sliding. Skin tears can happen while sliding during transfers because skin is pulled against a stationary surface.

To combat excessive or prolonged pressure and skin damage, try these seven methods:

- **Use a wheelchair cushion** on all sitting surfaces (wheelchair, couch, car seat, etc.) to help distribute or balance your weight over a greater area of your body.
- **Inspect all of your skin at least once a day.** Look for red or discolored areas, bruises, ridges or sores. Figure out what caused it and eliminate the cause immediately. Ask yourself: did it happen while sitting, lying, transferring or sliding? You can prevent further damage if problems are found early. Red areas can heal faster than sores.
- **Eat a nutritious, high protein diet.** Protein provides energy. Protein also builds and maintains organs, bones, muscles, blood and skin.
- **Use safe transfer techniques** to prevent falls and skin tears. Check for objects in your wheelchair before you sit in it. Make sure casters are forward and lock your brakes.
- **Clean your skin** with mild soap and water within 15 minutes of bowel or bladder accidents. Skin can be burned by the chemicals in urine and stool. Apply lotion as needed.
- **Exercise** to increase circulation, strength and range of motion.
- **Shift your weight** at least every 30 minutes while sitting. When you do pressure relief, you keep the blood flowing to your muscles and skin. Try doing pressure relief on a schedule at first. It will take about three weeks to develop a pressure relief habit. Don't forget to try many pressure relief methods until you find what works best for you.

For more information about pressure sore prevention, call Sharon Griffith at **800-459-1517** or **501-296-1784**.

Joint Contractures: Preventing a Common Problem

A contracture is a stiffness in a joint. A knee, elbow, hip, shoulder, wrist or ankle that once moved easily and freely now acts like it is stuck. And in a way, it is. Our joints move easily when the ligaments and muscles that hold them together are flexible and can stretch fully. They also move easily when the fluids and soft tissues inside the joint are moist and flexible.

Contractures tend to occur in the muscles where a joint bends, such as the spot where an ankle or knee moves. But they also can occur in the muscles that help move the shoulders and the hips or the muscles in the arms and legs that help these limbs move toward and away from the body and back.

Contractures affect the joints we use each day. So when contractures de-

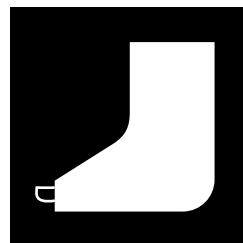
velop they can affect a person's ability to dress, eat, transfer, sleep comfortably, use a wheelchair or do any task that requires full movement of the arms, legs and hips.

You've heard the expression, "Use it or lose it." Well, that expression applies directly to contractures, for a joint that isn't moved often and fully loses its stretch and becomes stiff. The longer the joint stays stiff, the more likely it is that it will never move freely again.

Anyone can get a contracture. People who have had an arm or a leg in a cast can get a contracture in the un-

moved joints. People who spend a lot of time in bed because of an illness also become stiff in their joints. In a broad sense then, contractures develop when an illness or injury or the resulting pain reduces movement of the joints and muscles.

- Pay attention to proper posture when sitting in a wheelchair or propelling it. Poor posture affects the shoulder joints.
- Prolonged sitting can cause hip flexion and knee flexion contractures. If possible, lie prone on your stomach when resting during the day or night to stretch out the hip flexors. This posture will also stretch and extend your knee joints. To help your posture, use a proper back support in your chair and



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Spring Cleaning for Your Wheelchair

Spring is here and while you are getting yourself and your home in shape, don't forget your wheelchair. Just like a car, wheelchairs need maintenance. Maintenance is easy to do, although it can be a dirty job.



Cleaning is the first step. You can use any common soap-and-water based household product. Do **not** use any **petroleum-based** cleaner. As you clean off all of the dirt, note any repairs that need to be made. Does the chair fold and open correctly? Do the brakes work? Does the chair roll easily? Do all of the wheels touch the ground? Do the tires need air? Make sure everything works properly. If you inspect the wheelchair properly, most of these areas can be ruled out.

If you own a power wheelchair, use the same procedure. However, power wheelchairs have batteries that need inspection. Make sure all of the cables are tight and are corrosion free. If the terminals are corroded, you can clean them with baking soda and water (the recommended mixture is **1 tablespoon baking soda to 12 ounces water**).

When you are done, make sure the wheelchair operates correctly. You can probably fix a manual wheelchair but a power wheelchair is more difficult. Please leave all major repairs to the technicians, but don't forget the maintenance!

Scholarships Available

The Governor's Commission on People with Disabilities is again offering scholarships for students with disabilities. Students who want to apply must be enrolled in or intending to enroll in a college, university or vocational-technical school for the 2000-2001 year. Undergraduates and graduate students are eligible. Previous winners are eligible to apply for further assistance. Students will be required to take 12 hours per semester to receive the full amount. Partial scholarships will be awarded to students who, because of their disability, cannot take 12 hours per

semester. If you are interested, call **501-296-1600** or TDD **501-296-1672**. The deadline for getting applications in is **April 15**.

Persons with Spina Bifida are also entitled to apply for scholarships through the local and the national Spina Bifida Associations. Applications may be gotten by calling **501-978-7222**.

Don't forget to check with counselors at your high school and at the schools you may decide to attend for other sources of financial assistance.

New Challenges for a New Century

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give his always entertaining session on sexuality and spinal cord injuries. Experts from Arkansas Medicaid and Medicare will discuss their services and answer questions. **Dr. Tom Kiser** will talk about new technology and options in spasticity management, and **Dr. Alex Finkbeiner** will do the same on bladder management.

There is literally something for everyone in our program. Lunch time

will be a celebration of the 25th birthday of the Commission and, at the end of the day, Sunrise Medical will give away a Quickie Wheelchair (you must be registered and present to win).

Don't miss this year's conference! If you have not received a conference brochure in the mail, call us at **800-459-1517** or **501-296-1784** and we'll send you one.

Bernie Quell - New ASCC Case Manager

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Bernie and his wife Katherine have been married for eighteen years. Favorite leisure activities include woodworking, camping and gardening.

In the short amount of time he has been employed at the Spinal Cord Commission, Bernie has already begun meeting some of the individuals on his caseload. He looks forward to getting to know everyone and is excited about working for the Commission. We feel very fortunate to have an individual with such qualifications join the staff and welcome him aboard!



Bernie Quell is happy to be serving ASCC clients in S. Pulaski and part of Saline County.

Are You Prepared?

Disasters happen anytime and anywhere. When disaster strikes, you may not have much time to respond. A highway spill of hazardous materials could mean evacuation. A winter storm could confine your family at home. An earthquake, flood or tornado could cut water, electricity and telephone lines for days.

After a disaster, local officials and relief workers will be on the scene, but they will not be able to reach everyone immediately. Your family will cope best by preparing a disaster supplies kit **before** trouble arises.

To make your own disaster supplies kit, gather the following items and store them in an easy to carry container, camping backpack or duffle bag.



- A three-day supply of water (one gallon per person per day) and food that will not spoil.
- One change of clothing and

footwear per person and one blanket or sleeping bag each.

- A first aid kit that includes your family's prescription medications.
- Emergency tools including a battery-powered radio, flash light and lots of extra batteries.
- An extra set of car keys and cash or traveler's checks.
- Assorted special items, such as extra eyeglasses, and tubes for

your wheelchair, extra supplies for bowel and bladder care, diapers and formula for babies, etc.

Change stored food and water supplies and check medication expiration dates at least every six

months to assure freshness. You should reassess your family's emergency needs at least once per year.

One excellent source of additional information is the American Red

Cross (ARC). ARC offers detailed general disaster preparedness information, in both English and Spanish, for children and adults. To get copies of these educational materials, contact your local Red Cross chapter or see their website at www.redcross.org/disaster/safety/index.html.

- Jefferson County Chapter, Pine Bluff **800-775-7312**
- Northeast Arkansas Chapter, Jonesboro **870-932-3212**
- Western Arkansas Chapter, Fort Smith **501-782-1056**
- Central Arkansas Chapter, Little Rock **501-614-1021**

The Federal Emergency Management Agency (FEMA) also provides disaster preparedness information. FEMA provides specific information, in both English and Spanish, on safe methods of purifying water obtained from outside sources, hidden water sources within your own home and the best ways to store water for drinking. The regional office serving Arkansas is in Denton, Texas and may be reached at **940-898-5399** or you can check their website at www.fema.gov/y2k.

Joint Contractures: Preventing a Common Problem

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adjust or replace stretched-out wheelchair upholstery. A physical or occupational therapist can help you select the right type of back support.

- If spasticity is a problem, include weight-bearing exercises that strengthen the muscles opposing your tight spastic muscles.
- Be especially careful when stretching or exercising parts of the body in which you have limited or no sensation.

- People who use wheelchairs sit all day with their knees flexed. When possible put your feet up during the day to stretch and extend your knees. Pay special attention to your knees when doing your stretches and consider more frequent ROM knee exercises during the day, and lying on your stomach at night.
- Pay attention to your skin. Signs of skin breakdown, redness or broken skin offer clues to areas of the body that are not moving often enough.

- Commit yourself to a daily routine of exercise and passive stretches throughout your life.
- Remember, however, to be reasonable in the amount of stretching you do each day. Some stiff joints may simply need some gentle loosening up, rather than prolonged and extended stretches. Take care not to injure yourself.

This article was reprinted with permission from Second Thoughts, RTC on Independent Living, University of Kansas, 785-864-0590.

New Items in the McCluer Resource Center

The McCluer Education and Resource Center on Spinal Cord Injury has added several new items to its collection. If you are interested in checking out any of the resources, please call the Resource Center at **501-296-1792** or **800-459-1517**. Some of the new items include:

- ***I Don't Have to Make Everything All Better***, by Gary and Joy Lundberg, details six principles that help you empower others to solve their own problems while making relationships better.
- ***Life on Wheels: For the Active Wheelchair User***, by Gary Karp, covers important topics such as rehab, medical issues, social aspects of disability, sex and relationships and research.
- ***Gary's Story: What You Should***
- ***Know About Domestic Abuse and Spinal Cord Injury*** is a resource book and video for program planning concerning domestic abuse and spinal cord injured persons. It includes resources for health care professionals and individuals.
- ***KidAbility*** is a disability sensitivity and awareness video made by kids for kids.
- ***Building and Remodeling for Accessibility*** is a video which shows ideas for remodeling a home with modifications to the doors, kitchen, entryway and bathroom.
- ***OmegaTrac*** is a commercial video demonstrating a new power wheelchair featuring tilt and recline.

Shepherd Center Offers Adventure Skills Workshop Weekend

Individuals with disabilities can enjoy all their favorite outdoor activities, discover new ones and have fun during the annual Adventure Skills Workshop, **May 19-21, 2000**, at ASCCA, a fully accessible facility in Jacksons Gap, AL.

Sponsored by Shepherd Center's therapeutic recreation department, the three-day event is the only one of its kind, and includes adapted water skiing, scuba diving, fishing, canoeing, kayaking, jet skiing, four-wheeling, swimming, riflery, rope climbing and more. The fee is \$130, which includes meals, lodging, activities, instruction and a T-shirt.

For information or registration, call **404-350-7375**.

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